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Medical oncology patients' preferences with regard to health care: development of a patient-driven questionnaire

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Background: To improve quality of care for cancer patients, it is important to have an insight on the patient's view on health care and on their specific wishes, needs and preferences, without restriction and without influence of researchers and health care providers. The aim of this study was to develop a questionnaire assessing medical oncology patients' preferences for health care based on their own input.
Patients and methods: Items were generated using 10 focus group interviews with 51 cancer patients. A preliminary questionnaire was handed out to 681 patients of seven Dutch departments of medical oncology. Explorative factor analysis was carried out on the 386 returned questionnaires (response 57%).
Results: Focus group interviews resulted in a preliminary questionnaire containing 136 items. Explorative factor analysis resulted in a definitive questionnaire containing 123 items (21 scales and eight single items). Patients rated expertise, safety, performance and attitude of physicians and nurses as the most important issues in cancer care.
Conclusion: This questionnaire may be used to assess preferences of cancer patients and to come to a tailored approach of health care that meets patients' wishes and needs.
Key words: focus groups, patient-centred care, patient preferences, quality of care, questionnaire

introduction

During the last decade, patient-centred care is an issue of growing importance. Patient-centred care can be defined as ''care that is respectful of and responsive to individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions'' [1]. Due to an increasingly competitive environment, health care organisations need to deliver demonstrable quality of care. As a result, organisations need to make a shift in health care from being service centred and fragmented to being integrated and patient centred.

Cancer patients encounter physical and emotional problems that are substantially different from patients without a life-threatening disease. Evaluation of the best possible care for cancer patients concerns aspects that not only are medical but also include aspects that are directly linked to the patient's quality of life and to personal aspirations, values and quality of their relations and needs [2–4]. Several studies assessing cancer patients' satisfaction with care show that patients who are satisfied with their care are more likely to cooperate with their treatment, to continue their use of medical services and to maintain a good relationship with their physicians [3–7]. Moreover, greater patient satisfaction is associated with better clinical outcomes [3, 4, 8–11].

Furthermore, there is an increasing wish of patients to play an active role in the quality of care they receive and of health care organisations to involve patients to determine the spectrum of care they would like to receive [12]. For these reasons, value is increasingly set on patients' opinions on (quality of) health care [13, 14]. In truly improving patient-centred care, it is important to have an insight on the cancer patient's view on health care and their specific wishes, needs and preferences, without restriction and without influence of researchers and health care providers [15]. Generally, the patient's perspective is assessed with patient satisfaction questionnaires. Satisfaction studies are very important and reveal useful insights on the quality of existing care. However using satisfaction questionnaires may present a potential pitfall, because these instruments assess the quality of existing care and patients give their opinion within the existing framework (how was it?). Moreover, these questionnaires may reflect not only

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the needs and wishes of patients but also the perspective of the health care professionals [2, 16–18]. Furthermore, existing patient satisfaction questionnaires often provide highly skewed scores (75%–90% typically satisfied) casting doubt on their ability to measure patient dissatisfaction [11, 18]. In recent years there has been a trend away from global satisfaction measures towards a more detailed and individualised measurement of patient experiences [19]. Still, questionnaires used in this type of research are mostly developed by health care professionals with only a limited input of patients.

To identify the preferences of cancer patients in health care, it is important to ask them in a standardised unrestricted way (how should it be?) how they would design health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care workers. To our knowledge, no such instruments to improve quality of care exist for cancer patients in general. Therefore, the aim of this study was to develop a questionnaire assessing cancer patients' preferences for health care, based on their own input.

patients and methods

study design

The study consisted of two consecutive phases:

- a qualitative phase in which items for a preliminary questionnaire were generated through focus group interviews [20–22]
- a quantitative phase in which the preliminary questionnaire was tested in a large group of patients.

The research protocol was approved by the Medical Ethics Commission of the University Medical Centre Utrecht.

generating the preliminary questionnaire

patients and methods. Patients for the focus group interviews were recruited by medical oncologists of the Department of Medical Oncology of the University Medical Centre Utrecht during consultation at the outpatient clinic. In addition, patients were approached for participation during meetings of the Dutch Federation of Cancer Patient Organisations. Eligible patients should have a sufficient physical condition to participate in the interview and should also speak and understand the Dutch language. Eligible patients received a letter to inform them about the aim and procedure of the study and the importance of their participation. Participants were assured that their information would be kept confidential and that the data would be processed anonymously.

Focus groups consisted of four up to eight participants per group. During the interviews (lasting for 2 h), only one question was put forward by the panel leader: "How would you design health care if you were in charge?" Participants were stimulated to exchange individual opinions and experiences and to express feelings, views and ideas, without interference and control by the panel leader. They were explicitly asked to think out of the box and forget potential constraints.

The result of the focus group interview was a list of important health care aspects, conceptions, ideas and points of view. New focus group meetings were organised until data saturation occurred [23].

data analysis and generation of the preliminary questionnaire. Each interview was digitally recorded and a complete transcription was generated. A summary of the focus group interview was presented for approval to the participants. Next, the interviews were processed by the software program Nvivo© (Version 2.0; QSR International Pty Ltd., Melbourne, Australia 2002) for data processing and analysing such as classifying, sorting, arranging and coding large amounts of qualitative information. Text fragments were coded by two authors (HW and MdH), working independently. In case of discrepancy, consensus was reached through discussion. Codes of the text fragments were set down in an analysis diagram, consisting of three levels of decreasing detail: item level, scale level (items were categorised in scales) and topic level (scales were categorised in topics). For example, participants of the focus group interviews mentioned short waiting periods at the outpatient clinic (diagnostic tests, consultation, treatment) to be important. We categorised this as follows—item level: time spent at the outpatient clinic as short as possible; scale level: waiting periods; topic level: organisation of the hospital. Each statement explicitly expressed during the focus groups was classified in the analysis diagram in this way.

Each focus group interview was analysed according to this approach. During this process the classification was revised continuously. Items brought up in only one focus group interview were not included in the questionnaire. After 10 focus group interviews, data saturation was reached.

Based on the result of the focus group interviews, a preliminary questionnaire was generated. Items mentioned during the focus groups were translated into questions evaluating the level of importance on a four-point scale, ranging from 'Not important' (1), 'Somewhat important' (2), 'Important' (3), to 'Extremely important' (4). To specify for respondents what was exactly meant by a question, sometimes examples mentioned by patients during the focus groups were added (see Appendix, available as supplementary data in *Annals of Oncology* online). In these cases patients were only required to answer the main question.

Using this preliminary questionnaire, we also asked patients to indicate priorities by ranging the topics in order of importance. Additional items assessed sociodemographic and medical data-debriefing questions and an open-ended question asking patients if there were additional important topics in their treatment and care that were not included in the questionnaire. An instruction for completing the questionnaire was included.

testing the preliminary questionnaire

patients and methods. Before submitting the preliminary questionnaire to a broad sample of patients, a concept version was tested for feasibility in eight patients. Only minor changes of an explanatory nature had to be made.

Next, 100–150 questionnaires (depending on the size of the hospital) were distributed to Departments of Medical Oncology of the University Medical Centre Utrecht and six affiliated hospitals in the region of Utrecht, The Netherlands. Doctors and nurses of these departments handed out the questionnaires to an unselected sample of consecutive cancer patients. The questionnaires were encoded by hospital. A cover letter informed patients about the aim of the study and the importance of their input. Respondents were assured that their answers would be kept confidential and that the data would be processed anonymously. A phone number and email address to contact the project manager were provided. Respondents could complete the questionnaire at home and sent it back anonymously in a self-addressed pre-stamped envelope. A reminder was send to each patient after 4 weeks.

data analyses. Data were analysed using the Statistical Package for the Social Sciences version 14.0 (SPSS Inc., Chicago, IL). Factor analysis (principal component analysis) with Varimax rotation was carried out. Communalities, eigenvalues, scree plots, explained variance and factor loadings were examined to determine the factor structure. Items with a factor loading ≥0.40 were included into scales [24, 25]. Items with a factor loading <0.40 were selected or rejected for scale construction by two of the authors (HW and AdG) based on content validity, item scores (selected items >70) and applicability of the item for the entire patient population. Items that did not fit in a scale and were considered to be important and

relevant for the entire patient population were included in the final questionnaire as single items.

Next, the scores of scales and single items were transformed to a scale of 0–100 by using the following formula: $F=((i_1+i_2+\cdots+i_n)-n)\times 100/3n$ (n = number of items). High scores indicate high levels of importance.

Reliability of the scales was examined with the internal consistency coefficient (Cronbach's alpha) and the mean inter-item correlation coefficient (MICC) for each scale. Cronbach's alpha coefficient was considered sufficient if ≥0.70 [25] and MICC values should fall in the range of 0.15–0.50 [26].

results

generating the preliminary questionnaire

Ten focus groups interviews (N = 51 patients) were needed to obtain data saturation. Patient characteristics are depicted in Table 1. The interviews were conducted between June 2004 and December 2005. The focus group meetings proceeded smoothly and in an open and pleasant atmosphere. Patients were pleased to be involved in improving patient care. The focus group interviews resulted in a comprehensive list of relevant issues. At scale level these issues referred to appointments (two items), waiting periods (six items), privacy (five items), consultation and transfer (six items), main health care coordinator (one item), eating and drinking (five items), regulations about visitors (three items), safety (two items), services (two items), fellow patients (three items), content of communication (13 items), process of communication (seven items), rooms and services in general (eight items), rooms and services at the outpatient clinic (three items), rooms and services at the day care centre (two items), rooms and services at the ward (17 items), support in dealing with emotions (seven items), rehabilitation (six items), physician attitude (10 items), nurse's attitude (nine items), independency (10 items), physician expertise (four items) and nurse expertise (five items).

The preliminary questionnaire contained these 136 items, covering seven topics: organisation (35 items), communication (20 items), rooms and facilities (30 items), counselling and support (13 items), physician and nurse attitude (19 items), individual input/autonomy (10 items) and professional expertise (nine items).

testing the preliminary questionnaire

Between October 2006 and March 2007, questionnaires were handed out to 681 patients. In total, 396 questionnaires were returned, translating into a 57% response rate. Ten questionnaires were received after the cut-off date and were not included in the analysis. The data are based on responses from 386 patients. Patient characteristics are summarised in Table 1. Patients completing the questionnaire were older than the focus group patients and had more advanced disease.

The mean time to complete the questionnaire was 47 min. In all, 97% of the respondents found the questions comprehensible and 12% experienced completing the questionnaire as a burden. After completing the questionnaire, 96% of the respondents indicated it as important to participate in the study.

We found no statistically significant differences in mean item scores between hospitals. Therefore, factor analysis was carried out on the complete sample. This resulted in 21 scales (containing 115 items) and eight single items (Table 2). Five

Table 1. Characteristics of patients

Characteristic	Patients participating in the focus group interviews (N = 51) Percent	Patients completing the questionnaire (N = 386) Percent
Sex		
Male	33	35
Female	67	66
Age, years		
18–35	39	5
36–50	16	28
51–65	27	38
66–79	6	26
Unknown	12	4
Level of education		
Less than high school	NA	9
High school	NA	62
More than high school	NA	30
Type of cancer patients were treated for		
Gastrointestinal	6	21
Breast	18	45
Skin	0	1
Urological	20	10
Genital	10	10
Head and neck	4	2
Lung	4	1
Other	25	12
Unknown	14	0
Type of treatment (concurrent or previous)[a]		
Chemotherapy	35	78
Hormonal therapy	4	26
Experimental treatment	2	4
Radiation therapy	16	46
Chemoradiation	2	3
Surgery	35	72
Other	6	0
Unknown	37	0
Stage		
Metastases present	NA	72
Metastases absent	NA	28
Years since diagnosis		
<1	NA	38
1–5	NA	39
>5	NA	23
Previous hospitalisation		
Yes	NA	85
No	NA	15
Days of previous hospitalisation, weeks		
<1	NA	52
1–2	NA	31
2–3	NA	8
>3	NA	9

[a]Patients could tick off several answers.

NA, not asked.

Table 2. Mean scores of scales and single items,[a] Cronbach's alpha values and mean inter-item correlations (MICC) (for scales only)

Scale	Number of items	Mean score (SD)	Cronbach's alpha	MICC
Mistakes by professionals	2	90 (13)	0.61	0.44
Physician and nurse expertise	8	89 (11)	0.83	0.37
Consultation and transfer	3	84 (14)	0.67	0.40
Physician attitude	9	81 (13)	0.87	0.42
Patient file confidentiality	2	81 (18)	0.66	0.49
Opportunity to choose in care and treatment	5	80 (14)	0.79	0.43
Nurse attitude	7	78 (14)	0.88	0.51
Communication and information	12	77 (12)	0.84	0.30
Accessibility of services	4	77 (14)	0.66	0.33
Waiting periods	4	76 (16)	0.75	0.42
Support, counselling and rehabilitation	7	61 (20)	0.88	0.52
Alternate sources of information	4	60 (23)	0.83	0.55
Appointments	3	59 (18)	0.55	0.29
Rooms and facilities	9	57 (14)	0.77	0.27
Food and beverages	3	56 (19)	0.73	0.49
Presence of loved ones	2	49 (26)	0.75	0.60
Privacy	4	46 (22)	0.72	0.39
Patient habits	4	43 (22)	0.86	0.61
Patient interest groups	3	37 (23)	0.77	0.53
Conveniences	17	37 (16)	0.88	0.31
Fellow–patient interaction	3	17 (19)	0.57	0.30
Hospital equipment (SI)	1	84 (20)	–	–
Consultation at ER by own doctor (SI)	1	79 (20)	–	–
Written information (SI)	1	77 (21)	–	–
Support of a case manager (SI)	1	74 (24)	–	–
Continuity in care (SI)	1	72 (22)	–	–
Support by paramedical staff (SI)	1	68 (18)	–	–
Attention for nutrition (SI)	1	68 (22)	–	–
Leaving choices to doctors and nurses (SI)	1	66 (32)	–	–

[a]A higher score indicates a higher level of importance (range 0–100).
ER, emergency room; SI, single item; –, no Cronbach's alpha and MICC values calculated as this was not relevant.

items were deleted because of lack of applicability for the entire patient population. These items referred to prostheses and support devices (two items), information on hereditary types of cancer (one item), availability of physiotherapy (one item) and opportunity to participate in clinical studies (1 item). Eight items were deleted because they did not fit into a scale and/or had low items scores. These items referred to the possibility for patients or their loved ones to use the kitchen to prepare food (one item), possibility for patients to wait in the consulting room instead of in the waiting area (one item), decoration of hospital wards (one item), arrangements of beds in hospital rooms (one item), availability of rooms with an outside view (one item), costs of telephone and television rental (one item), telling of test results by the doctor in person and not over the telephone, even if that means that patients have to wait longer for the information (one item) and emailing health care professionals with a question (one item).

The internal consistency of the 21 scales was sufficient for most of the scales (Table 2). Six scales ('Mistakes by professionals', 'Consultation and transfer', 'Patient file confidentiality', 'Accessibility of services', 'Appointments' and 'Fellow–patient interaction') had a Cronbach's alpha value <0.70, probably due to the low number of items (two to four) in these scales. As the MICC was sufficient, we decided to keep these scales in the questionnaire.

The questions of the definitive questionnaire are shown in the Appendix (available as supplementary data in *Annals of Oncology* online).

Table 2 shows the mean scores of the scales and single items, ranked in level of importance. Most of the mean scores of the scales and single items were high, indicating the importance of the issues assessed by the questionnaire. Most important (mean score ≥80) in the opinion of the respondents were the scales 'Mistakes by professionals', 'Physician and nurse expertise', 'Consultation and transfer', 'Physician attitude', 'Patient file confidentiality', 'Opportunity to choose in care and treatment' and the single item 'Hospital equipment'. Of relatively low importance (mean score <50) were the scales 'Presence of loved ones', 'Privacy', 'Patient habits', 'Patient interest groups', 'Conveniences' and 'Fellow–patient interaction'.

Of the topics addressed in the preliminary questionnaire (before factor analysis), patients rated 'Professional expertise' as the most important aspect of health care, followed by 'Communication' and 'Counseling and support'.

discussion

In this study, a questionnaire was developed to assess medical oncology patients' health care preferences. This questionnaire is unique as it is completely based on the input of patients. The strength of our questionnaire is the way in which the items were generated. Patients were asked in a proactive and unrestricted way to identify their preferences in health care, without primarily paying attention to the feasibility of their wishes and without the influence of health care workers. The questionnaire is solely based on the input of 51 patients from 10 focus groups, ensuring that its content really represents the needs and preferences of patients themselves. No items were added by health care workers or researchers. This approach has been used by other groups, for example patients suffering from rheumatism, inflammatory bowel disease, diabetes or specific types of cancer, such as breast cancer [17, 27, 28]. However, as far as we know, this is the first systematically tested questionnaire to address this issue for cancer patients in general, based on their own input and focusing on preferences instead of satisfaction.

Our questionnaire differs from most existing questionnaires, as these questionnaires assess the quality of received care instead of patients' needs and preferences. Richardson et al. [29] reviewed existing tools to assess patients' needs and found only 15 instruments, most of which related to needs in relation to symptoms and problems and not primarily to preferences for health care. They concluded that none of the questionnaires was complete for all dimensions of needs assessment. In most cases, patients were involved only at that stage when there was already a provisional or pilot version of the questionnaire.

We experienced in the focus groups that involving patients in care innovation is fruitful, motivating and inspiring. It yielded a wealth of information and judging by the considerable response, patients were closely involved in this topic and willing to make a positive contribution. Patients could indicate clearly to what requirements care and treatment of oncology patients should comply. The relevance of issues provided by the focus groups is in line with previous research. The Picker Institute Adult Inpatient survey [28] resulted in eight patient-centred dimensions of care: 'Respect for patients values, Preferences and expressed needs', 'Coordination and integration of care', 'Information and education', 'Physical comfort', 'Emotional support and alleviation of fear and anxiety', 'Involvement of family and friends', 'Transition and continuity' and 'Access to care'. All these dimensions have been discussed in the focus groups and are well represented in the scales of our questionnaire.

An important conclusion of this study is that of all aspects of care, patients set highest value on treatment in a safe environment by skilled and communicative doctors and nurses. The highest scoring scales and single items are mostly related to the expertise, performance and attitude of doctors and nurses, indicating the importance of training and education. This is in line with other studies [3, 4, 9, 10, 30]. Highly qualified nurses and doctors are essential to provide optimal health care. Considerably less important are the organisational and environmental factors. Nowadays much attention is given to these factors (such as hotel services, comfort nursing, process management and all kinds of comfort-raising supplies). These types of effort are without any doubt important for the well-being of patients, but have a low impact when inadequate care (in terms of expertise and communication) is provided by doctors and nurses.

The results of this study are a valid and reliable starting point in care renewal processes and may be used to guide decisions in improving care for cancer patients. The mean scores per factor or item in order of importance may be utilised for an efficient and efficacious use of means by really focusing on the aspects of care that are the most important to patients.

Our questionnaire is applicable to medical oncology patients, regardless of type of cancer. It may be argued that such a questionnaire should focus on a specific type of cancer, as needs and preferences may differ between diagnoses. However, a multivariable analysis did not show a significant influence of type of cancer on outcome (H. Wessels, submitted). Therefore, our questionnaire can be used in heterogeneous groups of cancer patients.

Although it took patients a mean time of 47 min to fill out the questionnaire, compliance was good and few patients found the questionnaire burdensome. The length of the questionnaire makes it unsuitable for use in daily clinical practice. If used for that purpose, a shorter version will have to be developed.

The questionnaire performed well with regard to psychometrical properties and had a high level of content validity (as illustrated by the high mean scores of scales and single items). As there is no 'gold standard' to measure patients' needs and preferences, its criterion validity could not be assessed.

A possible limitation is the relatively small sample of typical-age cancer patients in the focus groups. A comparatively large group of younger patients (<35 years) participated in the focus group interviews. It is possible that the items might have been slightly different if more age-representative focus groups had been used. Younger patients may differ with regard to needs and preferences as compared with their elder counterparts. In the focus group interviews, young people expressed specific needs and wishes concerning care and treatment, related to their phase of life and differing from those of elder patients. Further research should focus on differences between age groups.

Obviously, the results of this study apply at group level. Patients have a much differentiated range of specific needs in what they expect of cancer care, but these needs do not identify a 'uniform' patient. Although all cancer patients suffer from a life-threatening disease, they differ in biological, cultural, psychological and socioeconomic respect from each other. Moreover, each patient has his/her own frame of reference modifying their needs and preferences in health care. Clinicians, therefore, always need to customise their service.

This questionnaire may be used to assess preferences of cancer patients and to come to a tailored approach of health care adapted to their wishes and needs, either at the group level (for example tailored to gender) or at the individual level. (Departments of) Hospitals may need to make changes in their health care based on such assessments.

In future research, the items of the questionnaire may be used as a basis for a questionnaire to assess the experiences of patients on the most important aspects of care.

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supplementary data

Supplementary data mentioned in the text is available in *Annals of Oncology* online.

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